Statement for LTC Forum

It is odd to be standing here on behalf of the tribes, but I am honored to speak their concerns on their behalf.

My name is Shelly Zylstra. I am the Planning Director for the Northwest Regional Council, an Area Agency on Aging in Region 3 serving Island, San Juan, Skagit, and Whatcom Counties and six Indian Tribes: Lummi, Nooksack, Samish, Sauk-Suiattle, Swinomish, and Upper Skagit. For over 12 years, the Northwest Regional Council has operated a Tribal Outreach program where our employee, a tribal member, circuit rides to each tribe to meet with and "visit" elders. During her visits, she engages them in conversations which screen them for needs, and offers solutions to problems by connecting them with Long Term Care services. She assists with paperwork, collects necessary documentation, acts as a notary, and communicates problems and "attaboys" to service providers, case managers, or DSHS Social Workers. It is a simple program, and it works.

In our time linking elders to services, we have encountered barriers in access. Some of them we have found solutions in existing policy which was simply not understood by line staff, and other barriers we have not been able to overcome. In general, we have spent substantial time explaining the barriers to both tribal people and policymakers. I have been asked to list some of the barriers for you today. In no particular order:

1. Some elders do not have birthdays. Elders from very traditional families may have a birth season, but no birth certificate or actual date. This makes eligibility workers very unhappy. The solution is to ask the elder to pick a birthday, and stick with it!

2. Indian marriages may have no documentation other than community knowledge and a dozen children. The asset eligibility for COPES is dramatically different for married and for single people.

3. By and large, Management Bulletins, Information Memoranda, and eligibility information do not include information which clearly state that Tribal Trust Land is not attachable for estate recovery. Many otherwise eligible individuals have turned down services because they are worried about losing their Trust Property.

4. Many tribal communities did not pay into social security or Medicare. Individuals who are currently retired do not have access to either if they worked solely for the tribes. For this reason and in recognition of the sacrifices the elders have made on behalf of the community as a whole, some tribes have a "per capita" payment for elders which is just enough to keep them ineligible for Medicaid Long Term Care Services. Certainly the income level for eligibility is federally-defined, however the interpretation of family size supported by that income is somewhat flexible. It is not unusual to have an elder's income supporting extended family members, even though they may not live in the same house and even though the custodial support of grandchildren is informal.

5. Many elders have a small, but hard won sum of money which is stashed away to pay for their funeral. It is deemed appropriate for Medicaid applicants to have a "pre-paid funeral plan" but the traditional burial for an Indian Elder may include feeding large numbers of people for several days and a "giveaway" as part of their funeral plans. Elders would never even consider spending this money on anything but their funeral, but the money makes it impossible for them to be eligible for long term care services without spend down.

6. The first step for Medicaid eligibility includes a financial assessment. Elders often do not keep paperwork such as receipts for medical expenses, utility bills, or other essential pieces of documentation of income or expenses. They may not have bank statements because they may not have a bank account. They may hold title to several vehicles, none of which run. They may own several pieces of tribal land. They may be or have been financially exploited and be unwilling to disclose the information. Finally, as a rule, an Indian Elder is unlikely to want to disclose any financial information to a non-Indian.

7. The second step for eligibility is the CARE Assessment. This is conducted using a computerized instrument, in the elder's home, by a Home and Community Services Social Worker, usually in one session of about 2 hours. The elder may never have had a white visitor and likely was warned about white people when they were growing up. It is considered rude to ask lots of questions and you NEVER ask questions about bathing, toileting, or other basic needs without knowing the person well. Social Workers vary tremendously in their ability to provide culturally competent services. Behaviors such as "redirecting", and "active listening" in order to get the assessment completed are perceived as rudeness. Eye contact, so valued in white society, may not be appropriate with some elders, and total avoidance of eye contact is equally rude. Offended elders usually do not admit to Activities of Daily Living deficiencies and may simply not respond, stopping the process before it begins.

8. Elders and their families may be reluctant to call white case managers to tell them of significant changes in their abilities. It is not unusual to find elders in much different circumstances at the required once-a-year assessments.

9. Indian Elders do not generally have a choice between an Individual Provider or a Home Care Agency Provider since few home care agencies have Native workers and few elders will accept anyone else.

10. Activities of Daily Living for Indian Elders should include transportation to cultural events rather that "essential shopping". To an Elder, funerals, namings, and other cultural activities are far more essential than shopping.

11. The CARE assessment does not allow sufficient time for gathering and cooking traditional foods and likely underestimates the time it takes to cook and heat with wood, perform any activity in substandard, crowded housing, and the wait time at clinics where there are no appointments.

12. Services performed by the tribe for their elders should never be considered "informal support" if there is a way to establish a contract with the tribe to reimburse them for it. By considering these "met needs" and not providing reimbursement, the elder loses hours and the clinic or other tribal program continues to spend scarce tribal resources to supplant Medicaid dollars.

13. IHS, Medicaid, and Older Americans Act are all "payers of last resort". Sorting out who will pay often delays essential services and causes unnecessary confusion about whom is responsible for providing services to elders.

14. Mainstream Older Americans Act services prohibit serving individuals under the age of 60. In the same Act, Title VI (Services to American Indians and Alaska Natives) elders are tribally defined. This means that an elder who receives services through Title VI on the reservation would potentially be denied similar services in town and the service system off the reservation is much more extensive than the service on the reservation.

15. Senior Citizens Services Act (state) funds also target people age 60 and over. In addition, these flexible funds to serve older adults in Washington State are extremely limited and need to be increased to serve older Indians without the age limitation they currently have.

16. While we tend to have culturally appropriate services or providers when culture is accompanied with a language barrier (Spanish and Korean Meal Sites; Russian-language Social Service personnel), it is unusual to have culturally-matched services or personnel where language doesn't present a barrier. The history and life experiences that many elders have, presents a huge barrier when the access is through a white face particularly if that face is culturally incompetent and cannot even pronounce the name of the tribe correctly.

It is not my nature, nor my intent to leave a bleak picture of elders and the tribes. Care of elders is a distinctive value held universally by our American Indian Citizens and we can learn a great deal from them. It is clearly possible however to assist tribes as they care for elders who are very low income, frail, and unable to count on informal support. Working together to identify barriers and establishing policy to eliminate them is an important step toward equal access for all citizens of Washington State.